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Disaster Preparedness for Families with Children who have Special Health Care Needs

Frequently Asked Questions

In 2005, the Family Initiatives Program within the Massachusetts Department of Public Health's (MDPH) Center for Community Health worked collaboratively with MDPH's Center for Emergency Preparedness to hold a series of 'community conversations' throughout the Commonwealth. The purpose of these meetings was to assist families, whose children have special health care needs, to proactively plan for disasters within their community. This 'frequently asked questions' document has been developed to provide responses to questions/concerns that were raised by participants, and as act as a starting point for a new series of community conversations MDPH will convene in the summer of 2006.

1) How will I get my child's medication filled/refilled in an emergency if pharmacies are closed or the mail is not delivered?

Many questions and concerns have been raised by parents with respect to how individuals can have their prescriptions filled/re-filled during a disaster.

The Massachusetts Department of Public Health (MDPH) is working with other state partners on issues around access to prescription medications during a disaster. At this time, MDPH has the following recommendations:

- a) Develop a family or personal disaster plan. A sample disaster plan can be found on the MassSupport website at: http://www.mass.gov/samh/pdfs/dph_family_displan.pdf. You may also call MassSupport at 1.866.237.8274 for a copy. In addition, you may also obtain this plan through Family TIES (<http://www.massfamilyties.org/>), or 1.800.905.TIES (8437). These plans are available in English, Chinese, French, Haitian-Creole, Italian, Russian, Khmer, Greek, Portuguese, and Spanish.

- b) Develop a family or personal disaster kit. In this disaster kit include clear copies of your driver's license (or other form of government issued ID) and current prescription medication labels for you and your child. Make sure the following prescription information can be read on the prescription labels: name of child; prescribing physician; name of pharmacy; dosage; and instructions.

Also include a copy of your health insurance card. If you or your child has any allergies or needs special accommodations include this information in this kit.

It is also recommended that you include things like bottled water, foods that do not need to be cooked or refrigerated (crackers, tuna fish, peanut butter, etc.), a radio with batteries, and warm blankets and clothing. It is a good idea to include recent color photographs of your children in your kit. These things should be stored in a place that is easy to access and your kit should be examined occasionally to be sure that everything is still usable. Your kit should be in a waterproof container. Children can make their own kits, with activities that are of interest to them. Remember to replace any items you take out/use from your disaster kit.

- c) Make sure your regular pharmacist knows that your child has special health care needs. Give the pharmacy a copy of a letter from your child's health care provider that explains your child's special needs. Include a copy of this letter in your disaster kit.

Ask your pharmacist how they would continue to provide services in a disaster. You may want to consider contacting your health insurer to find out if you are able to order a three-month supply of medication by mail.

2) What if my child's medicine is at home and my child is at school during a disaster?

Consider contacting your child's teacher/provider/school nurse about developing a 'portable disaster kit' for your child. This kit can include a Family Emergency Card. One such Family Emergency Card is available through MassSupport at 1.866.237.8274. *(See Response #1 for more information on how to contact MassSupport)*. Inform your child's teacher/provider/school nurse about your child's portable disaster kit.

Be part of any school-based emergency planning activities and remind the planning members of your child's medication/healthcare needs. Be sure to keep the school or childcare program informed of any medication/healthcare changes for your child.

State law requires that all public schools have an emergency plan that addresses a variety of emergency situations. Families are encouraged to be proactive. Check with your school nurse or the local special education director in your district who is responsible to have this information and request a copy. If you do not know who this person is, contact your local school or town/city hall. Read the plan and share your comments. Also, your child's school nurse may have information to share with you. In addition, the Massachusetts Department of Public Health's School Health Services division has more information on their website here:

<http://www.mass.gov/dph/fch/schoolhealth/index.htm>

3) *What if my child uses life-sustaining technology such as a ventilator or oxygen and my electricity goes out?*

You may want to contact the company (known as a durable medical equipment vendor) that provides you with this equipment to find out what kind of emergency plans they have in place. Ask how they will continue to provide services in the event of a disaster. Inform your local utility companies of your child's medical technology needs and ask about their emergency plans. Contact your local 'first responders' (e.g., Emergency Medical Service (EMS), fire, or police). If you do not know who your local first responders are, contact your town/city hall and ask. If possible, try to secure a portable generator for your home. You may also want to complete a 9-1-1 Disability Indicator Program form, which lets first responders know about your child's special needs before they arrive at your home.

Information about this program can be found on the Statewide Emergency Telecommunications Board website here:

http://www.mass.gov/portal/site/massgovportal/menuitem.8df13acb79c731c14db4a11030468a0c/?pageID=eopsterminal&L=5&L0=Home&L1=Crime+Prevention+%26+Personal+Safety&L2=Report+an+Emergency&L3=Enhanced++911&L4=About+E9-1-1&sid=Eeops&b=terminalcontent&f=setb_disability_indicator&csid=Eeops

You may also contact the Statewide Emergency Telecommunications Board about this program at 508.828.2911 (TTY 508.828.4572).

4) *How can I make sure my child who uses a wheelchair can get out of a building in an emergency when the elevator is not available?*

Let your neighbors know that your child uses a wheelchair and that you would need help to get out of the building if the elevator were not available. Contact your local 'first responders' (e.g., Emergency Medical Service (EMS), fire, or police) about your child's needs. If you do not know who your local first responders are, contact your town/city hall and ask. MDPH is working with many EMS companies to develop partnerships with families before emergencies occur. A list of some EMS companies with contact names and information is available from MDPH. Please contact Janet Berkenfield for more information about this list. Ms. Berkenfield can be reached at 617.624.5088. Register with the 9-1-1 Disability Indicator Program, which lets first responders know about your child's special needs before they arrive at your home. *(See response # 3 for more information about this program).*

5) *How will I know where and when to pick up my child with special health care needs in an emergency?*

Develop a personal emergency plan with the school, childcare program, or other caregivers to determine where and when to pick up your child. Ask how emergency messages/instructions would be sent to you. Make sure that the school, childcare program, or other caregivers have correct contact information for you and that you have their correct contact information.

6) In an emergency, how can I make sure emergency workers know that my child is non-verbal and non-ambulatory?

Develop relationships with your local ‘first responders’ (e.g., Emergency Medical Service (EMS), fire, or police) about your child’s needs. If you do not know who your local first responders are, contact your town/city hall and ask. Register with the 9-1-1 Disability Indicator Program, which lets first responders know about your child’s special needs before they arrive at your home. *(See response # 3 for more information about this program.)*

It is also good to develop a network of family/friends who can (with your permission and in your absence) explain your child's special needs.

Have your child carry a Family Emergency Card in his/her backpack. *(See response #1 for information on how to contact MassSupport for a Family Emergency Card)*. Be sure that all caregivers know and can tell first responders where to find this information.

7) Are all emergency shelters accessible for wheelchairs and persons who may need additional help during the emergency?

The Americans with Disabilities Act of 1990 (<http://www.usdoj.gov/crt/ada/emergencyprep.htm>) requires local government emergency preparedness and response programs to be accessible to people with disabilities.

Check with your local emergency management director to find out which shelters are the most readily accessible for wheelchairs and other assistance. To find out whom your local emergency director is, you can contact your city/town hall and ask.

Talk with your local emergency management director prior to an emergency so that they know what your child's special needs are and how to plan for them.

8) What would happen if there were an emergency during transportation to and from school?

Your child's Individual Educational Plan (IEP) or Individual Health Plan (IHP) should include planning for emergency situations both in school and while being transported to school. Explain your child's special needs and ensure that they are carefully communicated to all drivers. Ask to have a copy of your child’s Family Emergency Card *(see response #1 for information on how to contact MassSupport for a Family Emergency Card)* in the vehicle. Make sure that the transportation company has correct contact information for you and that you have their correct contact information. You should also contact your child’s teacher/provider/school nurse about this issue as well.

Consider planning for unexpected problems during the daily commute, such as a problem with the vehicle or traffic delays – pack extra water and a snack, to cover extended periods away from the destination. *(Also see response #2 about developing a ‘portable disaster kit’ for your child).*

If you have further questions, please contact:

MDPH - Family TIES

<http://www.massfamilyties.org/>

1.800.905.TIES (8437)

MDPH - School Health Services

<http://www.mass.gov/dph/fch/schoolhealth/index.htm>

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